inclusiondesignlab

choice and control

in disability support organisations

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## inclusion melbourne

Inclusion Melbourne is a community support organisation that has worked with people with an intellectual disability for more than 65 years.

Unlike other activity support day services, Inclusion Melbourne does not operate a centre and doesn't ask people to select activities from a list, follow a group schedule or stay in a centre. Instead, Inclusion Melbourne supports people to live a fulfilled life, to participate in community activities based on individual needs, wants and interests, and supports developing meaningful friendships within the local community. In other words, Inclusion Melbourne offers fully personalised support in the community.

Inclusion Melbourne's vision is to provide people with the opportunity to live in an inclusive community and to take their place in society as respected citizens.

## inclusion designlab

Inclusion Designlab is Inclusion Melbourne's engine room for research, innovation, communications and policy.

Our vision is to bring together people with a disability, community organisations, and the world's leading disability researchers to develop cutting-edge models of practice, choice and citizenship that shatter glass ceilings and promote a more inclusive Australia.

We do this by developing, trialling, and implementing new systems of support and communicating our insights through a range of publications and media. We are also significant contributors to public policy and government inquiries.

The products and services created by Inclusion Designlab contribute to the continuous development of the disability sector through evidence based practice, accessible materials, and vital training for families and collegiate organisations.

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# meet the contributors

### dr jane tracy

#### Director, Centre for Developmental Disability Health Victoria

Dr Jane Tracy is a medical practitioner and senior lecturer at Monash University. With over 20 years of experience in the developmental disability field, she has contributed greatly to the education and professional development of health professionals, practitioners and students across Victoria. Dr Tracy is currently the Director of the Centre for Developmental Disability Health Victoria (CDDHV). Dr Tracy and her colleagues have developed educational resources for the field, including CDDHV's inter-professional teaching and learning package Health and Disability: Partnerships in Action. Her commitment to the field and the significance of her study is prompted by her personal experience as the mother of an adult son with developmental disability.

The Centre for Developmental Disability Health Victoria was, until recently, an academic unit within the School of Primary Health Care at Monash University before moving to its new host organisation, Monash Health. Established in 1998 by the Victorian State Government, it aims to improve the health of people with developmental disability and the services available to them. The Centre is also involved in various research programs and provides scholarships in the field of Developmental Disability Health.

### professor tim stainton

#### Director, Centre for Inclusion and Citizenship, University of British Columbia, Canada

Professor Tim Stainton has dedicated his professional life to the area of disability, with an emphasis on intellectual disability. The Director of the School of Social Work at the University of British Columbia until 2016, Stainton's Doctorate investigated the rights of people with developmental disability and individualised funding. Stainton's experience is evident, having taught in various institutions from LSE and McGill to the University of Wales Swansea where he was Director of Social Work. His expertise has also been demonstrated in his published works concerning individualised funding, disability rights, history, ethics and theory. Stainton is currently the Director of the Centre for Inclusion and Citizenship.

The Centre for Inclusion and Citizenship was established in 2009 to support people with intellectual disability and their families to be fully included as full and equal citizens locally, nationally and globally. The Centre is committed to maintaining a culture of lifelong learning to support growth, innovation and excellence for all members of society. The Centre seeks to contribute to this goal through learning, research and knowledge exchange. Through partnership with the UBC School of Social Work, the Centre offers students support through internships, research assistant positions, access to professional development opportunities and scholarships.

# the NDIS and your organisation

The National Disability Insurance Scheme (NDIS) is an insurance scheme that will offer all Australians with disability access to the funds and support required to live fulfilling lives as equal citizens and community members. The Scheme is managed by the National Disability Insurance Agency (NDIA) and funded by the Federal and State governments. People who sign up to the NDIS are known as participants and commence their engagement by developing a support plan with the assistance of a planner. Unlike Australia's previous disability funding systems, in which an often insufficient amount of funding was distributed to support organisations, the NDIS will see funds go directly to participants in order to purchase reasonable and necessary supports.

The NDIS will therefore offer people with a disability increased choice and control via self-management of their support funding and the ability to shop around for the most suitable supports. The scheme will establish a new partnership and transactional relationship between people with a disability and disability support organisations. More than ever, disability support organisations will need to function as enterprises – businesses – that exist in a free market environment and accordingly will need to offer value for money and have firm boundaries around their core business and strategic planning. This is a significant challenge for the hundreds of small to medium sized charitable organisations that form the current support system.

The NDIS website is **www.ndis.gov.au** and the My Access Checker for prospective participants can be found at **https://www.ndis.gov.au/ndis-access-checklist**

# consumers in a marketplace

The NDIS will enable participants to identify and procure supports that allow them to fulfill the goals agreed in their plan. However, participants will also be consumers in a marketplace, looking for competitive prices, value, and assurance that the support organisations they choose are person centred and of a high quality.

The first two volumes in this NDIS Readiness for Disability Support Organisations series have focussed on the internal composition of organisations. This volume introduces NDIS participants as consumers who will have the power to demand greater flexibility from support organisations.

While individualised funding schemes exist in countries like Canada 🇨🇦 and the United Kingdom 🇬🇧 and have been available in Australia for more than a decade, insurance models that provide funding according to need have existed for some time in countries like Germany 🇩🇪 and Sweden 🇸🇪 – though not on as large a scale as the NDIS. Australian transport accident and workcover schemes operate using an insurance model. The experiences of NDIS participants in the NDIS marketplace will be viewed with interest by policy experts and disability advocates around the world.

# the NDIS: what's happened so far?

## to 1 july 2016

Approximately 50,000 plans were approved across all states and territories, with many of these being reviewed several times. Satisfaction was between 90 and 95%.

## from 1 july 2016

Full rollout commenced across several large population areas across the country, providing NDIS coverage to millions of Australians.

# what has **inclusion** melbourne *ɯ* learnt so far?

## Transport

▸ The NDIS includes the potential for money for transport, however this will be capped.

▸ Transport funding will be paid directly to participants according to their costed plans. Support organisations will not receive direct transport funding, nor will they receive money for administrative or incidental transport costs.

▸ Any funds received for transport from the NDIS will cause participants' access to mobility allowance payments to be revoked.

## Natural supports and volunteering

▸ The NDIS does not currently cover the costs involved in managing natural supports and volunteering. Organisations that aim to transition people from paid supports to natural community-based supports will need to work closely with supportive advisors to ensure costed plans allow for support coordination for natural supports so that such arrangements can continue. While one-to-one paid support will be a progressive step for participants from out-dated group day service programs, participants who have already grown accustomed to a personalised and inclusive support model may not find this to be such a progressive step.

## Preparation for planning meetings

▸ 54% of people who did not pre-plan before their first planning meeting in the Barwon trial site (Geelong, Victoria) did not receive a plan that met their needs.

▸ Several NDIS Readiness for Families training programs are available across the disability sector, however families need to find these and register for them as not all organisations offer such programs to their service users.

▸ Service users have the freedom to engage as many support and service organisations as they like. Many have chosen to leave their service, particularly if they were not supported in the planning phase of their NDIS engagement.

▸ The free market nature of the NDIS means that people with disability who do not have the support of family or committed advocates will potentially experience greater vulnerability when seeking necessary supports.

## Contact with the NDIS

▸ The NDIA focuses on the NDIS participant, not support organisations. As such, organisations should not expect to be contacted by the NDIA or included in planning or information gathering processes unless the participant specifically requests this and the NDIA agrees that this is appropriate.
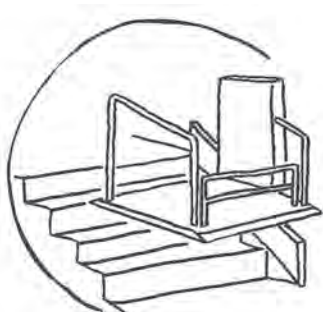
# what's the bottom line?

In the NDIS, participants will be legally entitled to funding:

> for all "necessary and reasonable" supports

> as determined by a costed plan developed in consultation with an NDIS planner

Whereby participants will receive funding:

> on an ongoing basis for the supports (including aids, modifications and staff) they need

To be purchased from the service providers:

> of their choice

With funds managed:

> by the person, by the NDIA, or by a nominated intermediary / specialist plan manager

With the costed plan being:

> open for review and modification as determined by changing needs and outcomes

# jane and nick: working with support organisations

When Jane's adult son Nick first moved into supported accommodation, the ride was a little bumpy.

Staffing was inconsistent, ever changing and irregular. It was hard for both Nick or his family to develop relationships with staff or a sense of security at the house. When Jane called the house, some of the staff had to ask: "Which one is Nick?"

Jane prepared a schedule for Nick that required accommodation staff to navigate transport, support for outside commitments such as medical appointments, recreational and social activities, and regular communication with family.

> A person-centred practice model that focusses on the goals of participants, strong family engagement, and a problem solving approach to meeting the specific support needs of each person is vital.
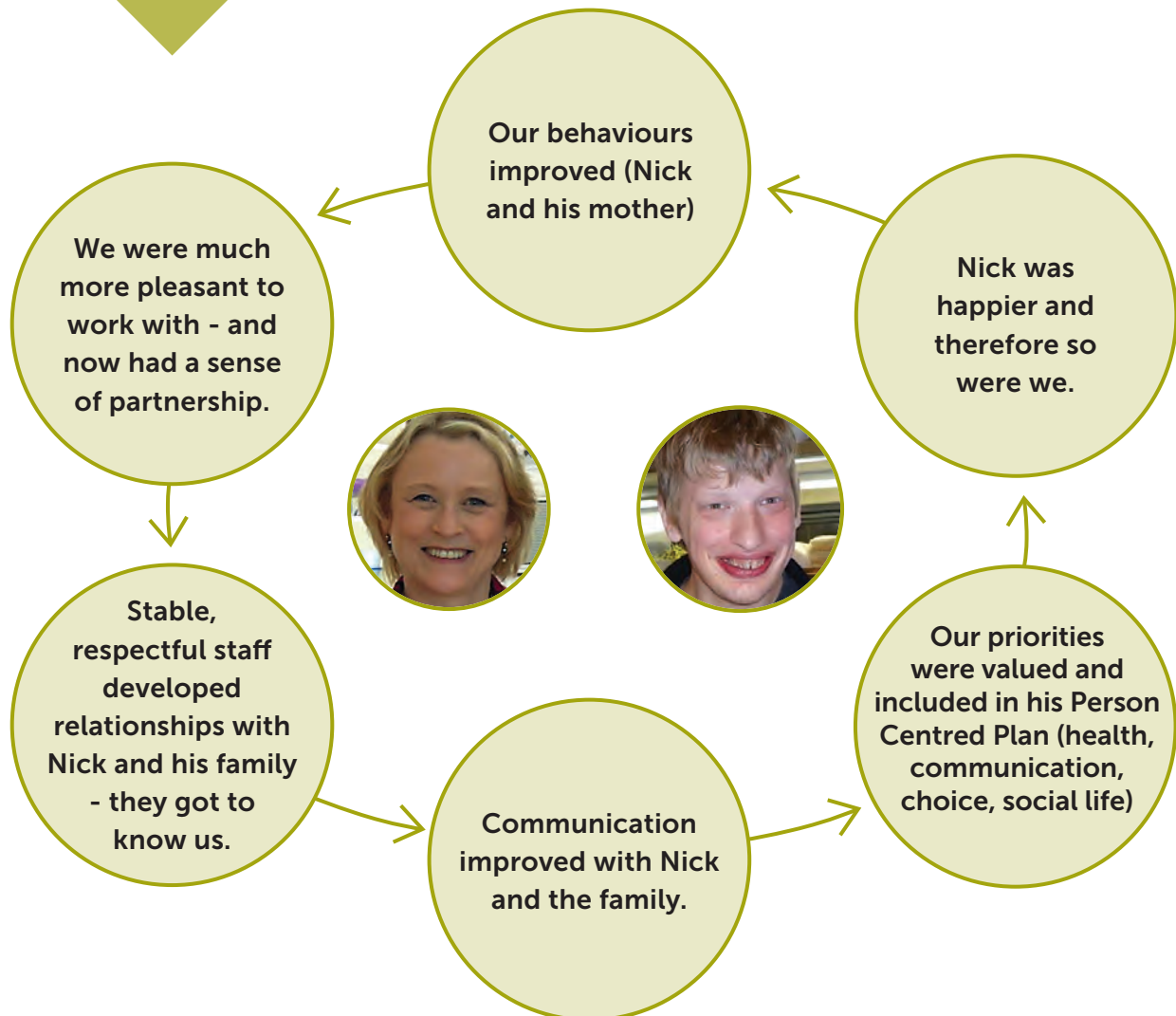
> In the past, many people with intellectual disability were tied to their support organisations. Sometimes this involved living in two completely different – or opposing – systems. Day services and accommodation services sometimes do not communicate with each other and may even provide support according to contradictory plans. Consumers in the NDIS will be free to disengage with any support providers that operate in this manner.

The schedule regularly failed to be adequately executed. While Jane had assumed interactions with family, day service, accommodation and other activities would be smooth, the staff at Nick's home were simply unable to live up to these expectations.

Nick's relationship with Jane was neither valued nor respected by accommodation staff. Nick's relationship with his girlfriend was questioned, despite it being fully supported by Nick's family and day service. Important events run by the day service were often ignored by the accommodation staff, particularly social events that were of deep importance to Nick.

**The message being sent by the accommodation to Nick's family was to back off.**

Jane needed to be a strong advocate for Nick in order to support him achieving his goals.

> Relationships are central to person-centred support. A key role of support staff is to facilitate and support a person's relationships to flourish sustainably. Under the NDIS, consumers who do not feel that their relationships are supported may seek support elsewhere.



"I would not back off. I developed a reputation as *the parent from hell!*"

When stable staff routines were established and Nick's relationships were respected....

Our behaviours improved (Nick and his mother)

We were much more pleasant to work with - and now had a sense of partnership.

Nick was happier and therefore so were we.

Stable, respectful staff developed relationships with Nick and his family - they got to know us.

Communication improved with Nick and the family.

Our priorities were valued and included in his Person Centred Plan (health, communication, choice, social life)

As the cycle on the previous page developed, stable and respectful staff developed relationships with Nick. Nick's family felt as though an immense weight had been lifted; they wanted to be able to support him and help him grow through life without having to be responsible for micromanaging his home life and his support.

The bad reputation that Nick had developed – wrongly named "behaviours of concern" – melted away as his home life improved. Nick was increasingly invited to participate in activities he enjoyed and enjoy and communication with support staff flourished.

## What does the NDIS mean for me?

"A new beginning. New hope for a bright future for Nick with and without me. It means real respect for who we are and what we can contribute."

### Recognition

Becoming visible as important and valued members of the community.

### Agency

Being recognised as voters and consumers - as people worth wooing!

### Respect

For our contribution, our expertise and our knowledge.

### Entitlement

Understanding our rights to be supported and to participate in and contribute to our communities.

"It means **REAL RESPECT** for who we are and what we can contribute."

### REAL

Recognition and respect

Entitlement

Agency

Life and leverage

### RESPECT

Rights

Engagement

Support

Power and prospects

Education and employment

Contribution

Trust in a future

## 1. goals

The initial goals that Jane and Nick will bring to their engagement with the National Disability Insurance Scheme – before the formal planning process begins – look like this:

1. To be happy, healthy and safe, including related concerns such as good mental health, exercise, weight control and personal boundaries.

2. To speak, be listened to and be heard, including access to all of the devices, apps equipment and staff training required for this.

3. Autonomy – to be in the driver's seat.

4. To love and be loved, including social networks, nurturing relationships, a dynamic relationship with his girlfriend, and functional accommodation arrangements whereby his relational needs are met and his desire to see the people he wishes to see is supported.

5. Opportunities to learn, achieve and be proud, including having continued access to educational opportunities that are meaningful to Nick, like his art program.

6. To have adventures and have fun.
*Eg. Nick likes to try new things but for Nick, it is more important who he does things with rather than what he does.*

7. To have a good life – with and without his family.

## 2. planning

Nick and Jane will spend time engaging with the NDIS local area coordinator (LAC) to make sure they get the meeting they want, with the people they want, and with the ability to present their independently developed research notes and planning materials to the NDIA representative (a planner, information gatherer or Local Area Coordinator, LAC). The plan they receive will be costed and ready to be put into action.

## 3. actioning the plan

Individual disability support organisations will be contracted to deliver the supports in this plan. As the focus of support delivery will be goal attainment, families like Nick and Jane will only engage organisations that can deliver supports and services to this end.

# 4. exercising choice and control

Nick's family wants Nick to be healthy and happy but they want a service provider to do the monitoring to ensure Nick's day-to-day needs are being met.

Jane will look at creative and innovative support solutions for Nick to enable him to access a range of activities and opportunities in his community. Participants and their families will seek out organisations that choose to loosen the demarcated boundary between 9am-3pm and 3pm-9am services.

Many families are frightened of rocking the boat. Families and support organisations can collect examples of what has worked in other contexts. If organisations are willing to be creative in designing support arrangements, they should let families know this!

People with disability often experience great difficulty in having their relationships recognised, especially considering the 9am-3pm and 3pm-9am divide noted above.

Sometimes these relationships are not valued by community, accommodation or family, particularly meaningful relationships developed independently of family. Support organisations can work to valourise, validate and advocate for these relationships, creating a sense of multiple voices existing in the person's life. Routines can help preserve some of these relationships if required. They can also be included in pre-planning documentation and the plan.
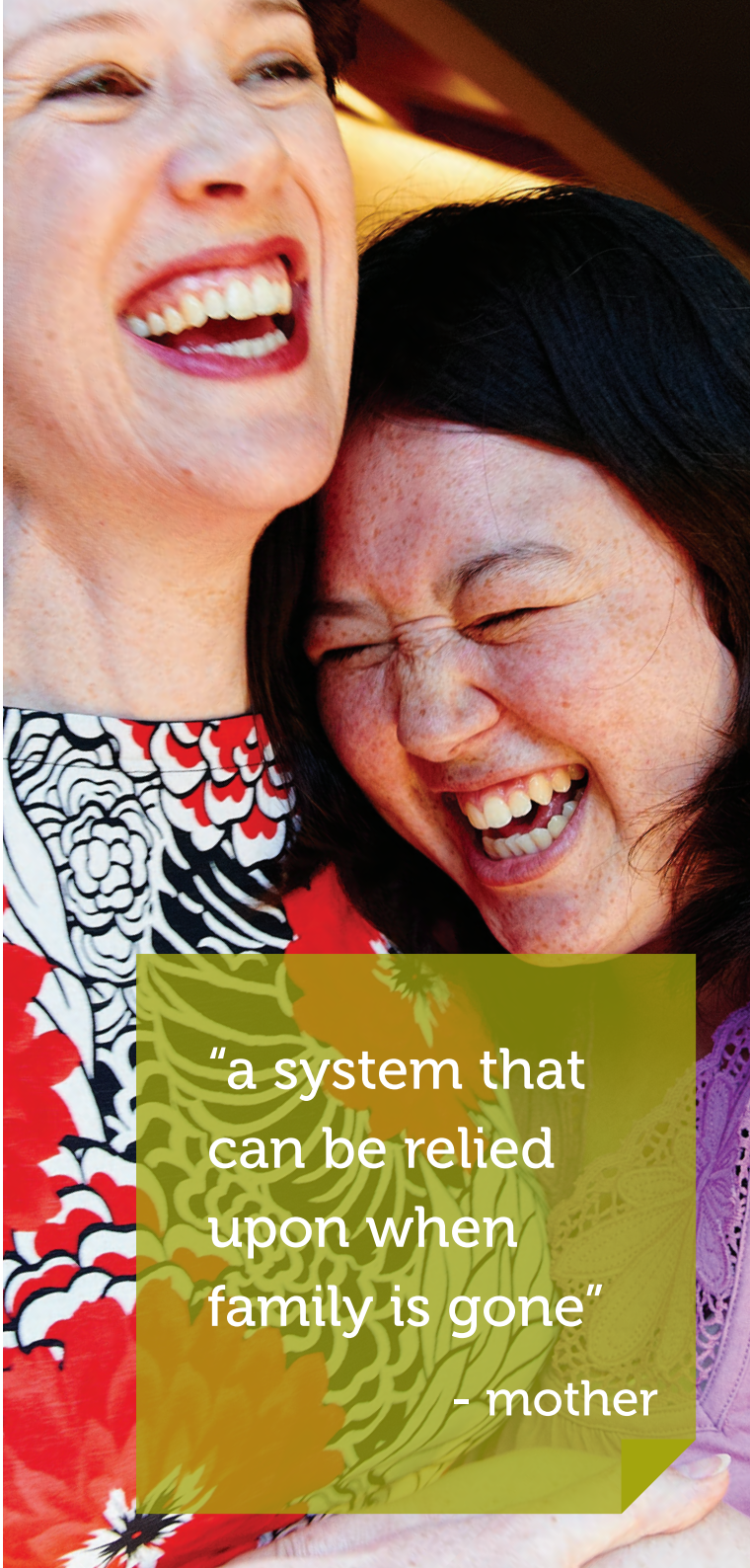
"a system that can be relied upon when family is gone"

- mother

# the journey of funding and personalisation

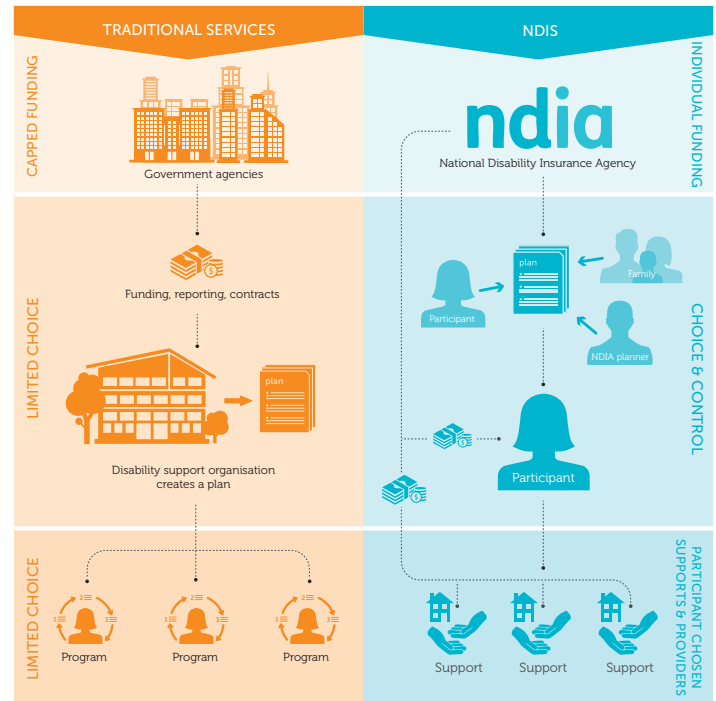## with professor tim stainton

### Pre-individualised funding era (to 2000s)

- Citizenship and legal personhood before the law questionable.
- Block funding. Individualised funding not available.
- Majority of people with disability encouraged to receive services but to be passive recipients of these services.

### Individualised funding era (2000s-2010s)

- Citizenship and legal personhood before the law enshrined in legislation.
- Limited funding.
- Legislation reflected in practice of some sections of sector.
- Rights based model of support delivery.

### NDIS era (2010s onwards)

- Citizenship and legal personhood before the law enshrined.
- Funding available for people to exercise full citizenship.
- Rights and entitlement.
- Market system and insurance scheme to drive improved practice.
- The National Disability Insurance Scheme explicitly aims to put into action the United Nations Convention on the rights of persons with disabilities.



TRADITIONAL SERVICES | NDIS

CAPPED FUNDING / LIMITED CHOICE / LIMITED CHOICE

Government agencies

Funding, reporting, contracts

Disability support organisation creates a plan

Program    Program    Program

ndia
National Disability Insurance Agency

INDIVIDUAL FUNDING

Participant    plan    Family    NDIA planner

CHOICE & CONTROL

Participant

Support    Support    Support

PARTICIPANT CHOSEN SUPPORTS & PROVIDERS

Professor Tim Stainton's three key elements of successful service user engagement for support organisations and government departments:

## 1. Personal decision making support

> Supported Decision Making and Representation. This includes the separation of legal capacity and mental capacity in laws and statutes, and allowing people with intellectual disability to exercise their rights to make their own decisions and to have the support necessary to do so.
> Family and Trust advisors
> Advocacy

## 2. Independent planning and facilitation support

## 3. Individualised funding

"Evidence shows that outcomes can't improve without these elements"

"The best model in the world can't compensate for underfunding.
The NDIS will surely test this idea!"

# supported decision making and planning

## choice and control

Choice and Control sit at the heart of the National Disability Insurance Scheme, however they can only become a reality for NDIS participants if they are supported to make decisions as individuals in the context of a supportive network. The NDIS will particularly benefit rural and regional communities who will now be able to access funds for services within their communities rather than having to travel to external communities.

## negotiation and allocation

Decision making must be led by the individual and their network. The creation of a costed plan should be a process of negotiation, rather than allocation. The NDIS will create broader potential for negotiation, moving away from support models of the past based on the allocation of resources depending on availability.

## group support to personalisation

Collective supports requires the grouping of people together based on resource availability and supposed common interests. While this may once have been viewed as a satisfactory reflection of good practice, the NDIS will see this model of convenience become outdated as resources are made available for support in genuine community based settings. Of course, trying to remove people from a group can cause transition problems if the individual, their family and network, and support agencies do not have a strong practice model. See Volume 1 of this series for more information.

## other tools for self-management

While financial intermediary services and support coordination services are available within the NDIS (visit www.ndis.gov.au for more information about self-management of funds), some additional models that may be helpful are Microboards and Circles of Support. Visit www.inclusiondesignlab.org.au/circles for more information.

# some ramifications of personalisation

**Choice and individualised funding in the NDIS have three significant ramifications:**

**1** | Person centredness, particularly around freedom and choice of daily schedule, can clash with staffing. A robust practice framework that sits at the centre of support organisations' operations can support person centredness.

**2** | Self-management may lead to support staff being recruited by organisations or families based on attributes other than formal qualifications in disability, experience, or practice. Organisations need to consider how they might respond to this trend.

**3** | The NDIS does not provide funding for administration within disability support organisations. The unit cost for supports and coordination will need to cover all administrative costs. Financial modelling from advisors and/or consultants may be required to ensure viability. See Volume 2 of this series for more information.

### Other areas of risk

➜ Lack of quality pre-planning and planning leading to the creation of plans that do not truly reflect the needs of the NDIS participant.

➜ The potential for participants to choose poor quality supports in the widely expanded disability support marketplace or supports that fail to meet their needs or expectations.

➜ A scarcity of supportive advocates during pre-planning. Some people will obtain support from their current support organisation or other consultants to consider and develop a list of desired goals and detailed support needs, while others will not and consequently may find little difference in their day to day lives.

Families that are already in relationship with support organisations and that seek assistance from those organisations to prepare for engagement with the National Disability Insurance Agency (NDIA) and the Local Area Coordinator (LAC) should be encouraged to focus on three key areas:

| The right assessments | Effective pre-planning | A strong voice backed by strong understanding of what your planning meeting(s) should look like |
|---|---|---|

Organisations are currently having conversations with the people they support to make them aware of an array of considerations, including:

## Leave

Support organisations will be able to claim a certain number of notional leave days (8 at time of printing, though highly likely to change during the NDIS rollout) if the NDIS participant is unable to receive contracted supports

## Contracts

Support contracts must include strong communication in as many scenarios as possible, such as leave, satisfaction, changes to schedule, changes to the NDIS plan, and reviews from allied health assessments

## Transport

Funding arrangements and responsibility for transport is shifting to participants and their families. Transport arrangements may require significant attention when planning a contract for support provision.

## Billing

As funds are now provided directly to participants and their families, bills and invoices will be sent to families, unless a financial intermediary is appointed in which case invoices may be sent to multiple parties.

## Desirability

Just as NDIS participants are consumers in a support market, support organisations will be able to set boundaries around their business operations. See Volume 2 of this series for more information.

# more from inclusion melbourne and inclusion designlab



## practice leadership in disability support organisations

NDIS Readiness for Disability Support Organisations - Volume 1



## driving up quality in disability support organisations

NDIS Readiness for Disability Support Organisations - Volume 2



## individualised supports

For more information about pricing and costing.



## it's my choice! toolkit

Guide to decision making and planning tools for people with disability, families, advocates and organisations.



## circles of support

Guide for family carers, friends and advocates who want to start a Circle of Support.



## seven approaches

Guide to support people, identify opportunities and connect with their community.



## your dental health

A guide to oral hygiene, dental health and the dental system for people with a disability, their families and carers.

inclusiondesignlab.org.au

inclusion.melbourne